

National Initiative for Glaucoma Control, Inc.

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TO: Founding Sponsors and Associates of the National Initiative on
Glaucoma Control, Inc.

FROM: Mike Gorman, Executive Director

SUBJ: Update on Initiative Activities - 1984

DATE: November 5, 1984

Since the Initiative's creation nearly a year ago, our energies have been carefully limited to two priorities:

1. Working closely with Members of the Senate and the House of Representatives -- particularly members of the Health Appropriations Committees to encourage additional targeted funds for glaucoma research and, equally as important, support of a health education and promotion campaign to take these research findings to the general public so that education about risk factors, the necessity for early diagnosis and our increasing treatment capabilities will motivate people to seek early diagnosis and treatment that, in many cases, will prevent blindness. We are acutely aware of findings that at least a million people in this country have glaucoma but do not know it. This is intolerable.

2. Recruitment of sponsors and associates whose interests, expertise and credibility would strengthen the Initiative's objectives.

Earlier in the year we began a fairly active campaign of recruitment for sponsors, but this had to be put on the back burner while we devoted almost all of our time to working with the Congress, since we found very few Members of the Congress who had any knowledge of glaucoma.

Mike Gorman, Executive Director of the Initiative, testified before Senator Weicker's Subcommittee on Health and Human Services early in April. He made a strong plea on behalf of the Initiative for increased attention to glaucoma. We were therefore delighted when on June 29th of this year the full Senate Appropriations Committee in its Official Report to the Senate, directed the National Eye Institute to prepare a special report on glaucoma for the fiscal 1986 hearings which will probably begin in March, 1985. Here is the key language in the Official Senate Report:

"The Committee understands that glaucoma is the leading cause of blindness in the United States today. An estimated 5 to 6 million people in the United States suffer from some form of glaucoma and the percentage of people with glaucoma will increase sharply as the population ages. Because in its early stages glaucoma is frequently without symptoms, people may be unaware that they have the disease until they have lost a considerable amount of visual function. Most forms of glaucoma cannot be cured, but through early detection and diagnosis and effective treatment, progression of the disease can usually be arrested and blindness prevented. Thus, the Committee directs the NEI to prepare a report on the possibilities and cost of a glaucoma control research initiative which will (a) develop the epidemiologic base for glaucoma screening, education and control programs; (b) support clinical trials and applied clinical research to document the most appropriate and cost-effective treatment methods for glaucoma control; and (c) support a health education and promotion campaign to convert these research findings into information about risk factors, early diagnosis, and treatment methods that will motivate the public to seek early diagnosis and treatment. This report should be presented before the fiscal year 1986 hearings."

Testifying a little more than a month later before the House Subcommittee, Mr. Gorman made a similar plea for adequate funds for glaucoma, stressing particularly as he did in his prior Senate testimony, the need for a broad public attack and promotion campaign to inform the general public about the risk factors involved in neglected glaucoma. On the House side several Members, including one who is being treated for glaucoma, expressed their puzzlement that we really didn't know how many people had glaucoma, nor were the American public aware that it was the major cause of blindness and the second most feared disease in the country -- exceeded only by fear of cancer. House Members were particularly critical of the Administration for proposing a miniscule \$91,000 increase for glaucoma for the coming year.

However, the National Eye Institute should be very pleased with the Congressional budget action. Its budget is increased from \$155 million in fiscal 1984 to \$181.6 million in fiscal 1985, a sharp increase of approximately \$26 million over the fiscal 1984 level. The generous Congressional increase compares with the Administration recommendation of only a two percent increase for the entire National Eye Institute for fiscal 1985 over fiscal 1984.

To give you an idea of the increasing involvement of the Congress in the promotion of efforts in the field of glaucoma, let me cite verbatim an actual colloquy between Dr. Kupfer and several Members of the House. Space does not permit but a small excerpt:

CONGRESSMAN GEORGE O'BRIEN. I recently had some surgery, and the condition developed because I have an inherited tendency toward glaucoma coming from my grandfather, and a very prominent surgeon in my area, Dr. Morimoto detected it. I had been on medication that controls the pressure, the eye drop medication business that you described; but I think it became a Catch-22 thing for me, because I have the impression that the use of that medication clouded the lens and required the surgery. I was also interested in your comments about laser treatment for glaucoma and I take it that having had the surgery on the lens, I am not a candidate for that kind of surgery, is that correct?

DR. KUPFER. What surgery have you had on the lens, removal of the lens?

MR. O'BRIEN. Yes, it was a cataract operation. It only occurred in one eye.

DR. KUPFER. Do you recall what medication you were on?

MR. O'BRIEN. Pilocarpine and something else.

DR. KUPFER. Timoptic?

MR. O'BRIEN. Yes.

DR. KUPFER. Probably there is no relation between the development of the lens opacity and the use of those drops. We have thousands of people on these medications, and although it is true that lens opacities do develop, they would develop in this age group anyway, and therefore, probably are not related to the medicine.

If the glaucoma existed prior to the cataract surgery, my impression is that laser treatment will still be effective, so this has not preempted the possibility of using that therapy.

MR. O'BRIEN. As near as the doctors can determine at Bethesda and back in Joliet, Illinois, there is no damage to the optic nerve thanks to the medication, but it is nice to have a disease you can control.

Literally, what is glaucoma, if the medication reduces the pressure down to a tolerable level? I would assume I am on the edge of it, but not there yet.

DR. KUPFER. What we are discussing is called open-angle glaucoma, because the outflow channels through which the fluid that is continually being produced in the eye appear to be normal. We know that they are not normal, however, in the sense that they present a greater resistance to outflow than normal, but when we look at the part of the eye where the fluid leaves, we cannot see any abnormality.

This form of glaucoma will produce damage, because if the pressure in the eye is maintained at a very high level for a long period of time, the pressure will have a damaging effect on the optic nerve, and the optic nerve carries the impulses from the retina to the brain.

The medication lowers the pressure and, therefore, removes that optic nerve from being at risk. So the lowering of the pressure controls the glaucoma but it doesn't cure it. It is similar to the use of insulin in diabetics; it controls but does not cure the diabetes.

I would be very happy to see you in consultation at the National Eye Institute. I still do see patients and my area of interest is glaucoma and has been for the past 30 years, so we could continue this discussion in depth. A letter of referral from your physician will initiate this consultation.

INFORMATION TRANSFER

MR. O'BRIEN. You are very kind. I confess a little more than an academic interest in your testimony.

I also like to hear you use terms like immediate clinical application, but that is generally true in all our pursuits. We are impatient with the people like you who are out there doing the job to see how quickly the things you develop can get to patients, the likes of me, for example.

Do you think that the results of research supported by the Eye Institute is getting out into the hands of doctors like my friend Dr. Morimoto and others?

DR. KUPFER. We feel that this is a responsibility, that we have an obligation to conduct basic research in the laboratory, and as soon as that research seems ready to be applied to a clinical problem, to test this possibility in the form of a clinical trial. But as soon as the results of a clinical trial are available, our job is not over. We must then make that information available to the practitioner, and we have expended a tremendous amount of effort and energy in making the results of our clinical trials known to the health care community.

For example, after the studies have been successfully completed, we mail a copy of the published scientific paper describing the results to every ophthalmologist in the United States. We conduct courses at the American Academy of Ophthalmology to disseminate this information, and we have press releases generated by the NEI and the participating clinics.

We make sure that the results of our studies are incorporated in the board examinations given to young ophthalmologists. Through these and other activities, I really think that we have successfully addressed our responsibility to move the results of research out into the practitioner community.

GLAUCOMA TREATMENT

MR. O'BRIEN. I am glad to hear that. This doctor is a superb surgeon, and I would like to think that you could help him all you could because he takes care of people like me.

I have one other personal inquiry, but it may have radiance beyond just myself.

The only thing I have given my grandson so far is that pressure in his eyes, and he is 12, very bright young boy, and I am concerned about him. Is there anything special to be done for people at that age?

DR. KUPFER. It is true, sir, that he probably is at greater risk having a relative with glaucoma than if he did not. I gather that there are no other family members with glaucoma?

MR. O'BRIEN. To date, we are aware of none. He is the oldest. My daughter told me that his pressure was considered to be rather high for a youngster that young.

DR. KUPFER. I would say that it would be important for his pressure to be checked every year. He should be closely monitored because, again, if we catch these cases early enough, we can control them. That is the hope at the moment, for early diagnosis and control, so that is what I would advise.

MR. O'BRIEN. The particular treatment then for myself and my grandson would be uniformly ---

DR. KUPFER. Medication, Sir.

GLAUCOMA IN BLACKS

CONGRESSMAN LOUIS STOKES. Doctor, you will recall that we also talked about the fact that glaucoma blindness in black males is much more prevalent. Can we talk about that for a little bit?

DR. KUPFER: I am happy to report that we have just funded a grant that will look into this very question and it has two parts. The first is to document very carefully whether there is this significant difference between blacks and whites with respect to glaucoma, so that we have a solid scientific base on which we can build. The second part will be an effort to identify what the risk factors are in the development of glaucoma in these two populations, whether the same risk factors apply to blacks as to whites or whether there are differences. This is a five-year study that will cost close to \$2 million.

MR. STOKES. I notice that your fiscal year 1985 budget request for glaucoma research is about \$12.7 million, which is less than a one percent increase over the current level. Will this amount permit you to fully explore all promising leads in glaucoma research?

DR. KUPFER. We have a very large non-competing figure in that 1984 budget because in fiscal year 1984 we began a major clinical trial, comparing the use of laser as an initial treatment in newly diagnosed glaucoma with the conventional treatment with drops. This has made the noncompeting line a little larger than usual. Nevertheless, we will be able to fund the major priorities in the glaucoma area with this minimal increase.

NEI to Convene a Panel to Prepare Senate Report

The Eye Institute has begun its process leading to the creation of the Report to the Senate Appropriations Committee. Following is an excerpt from the Minutes of the recent National Advisory Eye Council:

"Glaucoma. The Senate has requested preparation of a report on the possibilities and cost of a glaucoma-control research initiative. NEI plans to set up an outside panel of consultants for advice and suggestions on the exact form to be taken by this report (which is due before the FY '86 hearings). The panel would be composed of representatives of professional organizations having an interest in glaucoma such as (but not limited to) the American Academy of Ophthalmology, American Academy of Optometry, National Society to Prevent Blindness, and the National Initiative for Glaucoma Control. Other individuals with specific expertise in relevant areas will also be invited to participate."

This is an ideal opportunity for the Initiative and other organizations. We request that you advise us of your own interest and availability to serve on the NEI Report panel. We expect to have the opportunity to send at least one representative to the panel and possibly nominate several consultants or sub-committee members.

Our experience with congressionally mandated reports is that the report will be well received by the Appropriations Committee if it concentrates on pragmatic and attainable goals, and makes definitive recommendations in each of the areas specified in the report directive. Academic debate must be minimized while emphasizing positive actions that will begin to impact on the public in a minimum of time.

Please let us hear from you with your thoughts and suggestions. We want to work closely with the Eye Institute on this Report.

----- ADDITIONAL INFORMATION AND ACTION ITEMS -----

- Please send your recommendations for new sponsors.
We will soon list all sponsors on the Initiative letterhead.
- We expect to convene meetings of our sponsors from time to time and to establish an Executive Committee to meet more often.
- Mr. Gerald Wilson, Mr. Gorman's associate, will attend the AAO meeting in Atlanta, November 11-15. He will attempt to speak to each of you attending as schedules permit.